

GTC7.2014 Organise a test that uses genetic technologies

OVERVIEW

This standard is about recognising the indications for ordering a test which uses genetic technologies to inform clinical management, and the implications of the results of such tests for the individual and their family members. Here the term 'genetic technologies' is used to involve the direct analysis of genetic material (nucleic acid (DNA/RNA) or chromosomes) or the analysis of genomic biomarkers. The analysis may be on a single gene, multiple genes or may encompass the whole genome. As well as being used to analyse the genetic material inherited from parents, genetic technologies can also be used to analyse the genomes of cancers and infective organisms. Information generated by the use of genetic technologies can assist in: diagnosing a genetic condition, type of cancer or infection; predicting response to drug treatment, including adverse reactions; predicting susceptibility to disease; informing personalised management of an individual's healthcare. Genetic information can also be obtained from clinical examination, imaging and family history. For instance, a renal ultrasound scan in persons at risk of adult polycystic kidney disease could be defined as a genetic test in that it gives 'genetic information' but this standard is restricted to genetic laboratory tests as defined above. Tests using genetic technologies should be ordered only to assist a specifically identified aspect of management. It may not be clinically necessary to offer such a test to every individual with a given condition. This standard is applicable to healthcare staff in specific defined roles, who have received appropriate training. Users of this standard will need to ensure that practice reflects up to date information and policies. Version No 2

KNOWLEDGE AND UNDERSTANDING

You will need to know and understand:

1. the conditions caused by genetic or genomic alterations relevant to your area of practice, their symptoms, clinical signs and modes of inheritance
2. the range of services for individuals with, or at risk of, genetic conditions in your area of practice, including specialist genetic services
3. the range and type of tests, using genetic technologies, available to inform clinical management of conditions within your area of practice
4. the uses, potential benefits, limitations and implications of testing using genetic technologies
5. local and national guidelines governing genetic testing
6. the current guidelines for genetic testing in children

- 7.the indications for testing for conditions relevant to your area of practice
- 8.the type of sample required by the laboratory for testing
- 9.the timescales involved in the testing process
- 10.that genetic and/or genomic information impacts not only on the individual but also on their immediate and extended family
- 11.cultural, ethical, legal and psychosocial issues relating to the use of genetic and genomic information
- 12.consent and confidentiality guidelines, including consent with regard to the sharing of genetic information with other family members for their benefit
- 13.that clinical samples may be stored for potential use in quality assurance, audit, research, education and training purposes

PERFORMANCE CRITERIA

You must be able to do the following:

- 1.identify, by using reliable information, whether a laboratory test using genetic technologies will assist the clinical management of an individual
- 2.ensure the indications in each case meet the testing criteria for the particular test
- 3.adhere to local and national protocols for testing
- 4.adhere to consensus guidelines with respect to testing children, asymptomatic individuals and adults with incapacity
- 5.ensure any genetic or genomic information you give to the individual is within the limits of your role, responsibility, knowledge and experience
- 6.explain to the individual the purpose and process of the genetic testing including realistic timescales, familial implications and possible unexpected results
- 7.discuss the ethical, legal and social implications relating to genetic testing
- 8.encourage the individual to ask questions and voice any concerns
- 9.respect the individual's rights and wishes relating to their privacy, beliefs, and dignity
- 10.obtain informed consent from the individual before ordering the test
- 11.agree with the individual the method of informing them of the results of the genetic test
- 12.seek agreement for the storage and/or the sharing of sample and test results for the benefit of other family members if appropriate
- 13.organise appropriate testing
- 14.complete all documentation ensuring all relevant information is passed on to the laboratory when ordering the test
- 15.ensure the result is reported to the individual and to others as deemed appropriate or essential and agreed with the individual
- 16.maintain the chain of confidentiality when passing information to other healthcare professionals

ADDITIONAL INFORMATION

This National Occupational Standard was developed by Skills for Health. This standard links with the following dimension within the NHS Knowledge and Skills Framework (October 2004): Dimension: HWB2 Assessment and care planning to meet people's health and wellbeing needs